Outpatient Care in Fairbanks: Supporting People with Schizophrenia

by

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Abstract

With the current lack of residential treatment facilities, long-term hospitalization, and mental health agencies that can fully support people with schizophrenia in Fairbanks, Alaska, there are many ethical concerns that must be addressed to best support clients with schizophrenia. The ethical considerations present in the success of outpatient care include: a) promoting the welfare of clients, b) utilizing plans that offer reasonable promise of success, c) understanding the limits imposed on the support networks of these clients, and d) the limitations of employment opportunities for these clients in an outpatient setting. Reviewing literature on the experiences of people with schizophrenia revealed three stages of treatment normally experienced: a) acute care, b) transition care, and c) chronic care. Areas most impacted for people with schizophrenia are socialization and work, memory and intelligence, suicide risk and other disorders, and interactions with family, friends and the community. In Fairbanks, Alaska where weather hinders socializing and available services are limited, building many strong support resources is incredibly important to give people with schizophrenia the best chance of recovery and a stable quality of life.

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With the decline in the number of psychiatric hospitals after the Community Mental Health Act (1963), community support has been adopted as the means to assist people with mental illnesses and disabilities by serving them in their local communities as well as creating small communities specifically designed for the support of people with mental disabilities. Previously treated in inpatient group or residential facilities, people with schizophrenia or other forms of psychosis are becoming more reliant on outpatient care and community living than ever before (Rudkin, 2003). As a result, treatment plans need to be developed that take into account external variables not found in controlled inpatient settings.

Understanding limitations of treating patients with schizophrenia in an outpatient setting is a clear ethical consideration for counselors working with these clients. The ethical considerations present in the success of outpatient care include: a) promoting the welfare of clients, b) utilizing plans that offer reasonable promise of success, c) understanding the limits imposed on the support networks of these clients, and d) the limitations on employment opportunities of these clients in an outpatient setting (American Counseling Association Governing Council, 2014). Counselors following any appropriate code of ethics need to be fully aware of the low rate of compliance and continued remission in outpatient therapy.

In 2013, the Fairbanks Daily News-Miner posted an opinion piece alerting the public that adults living with schizophrenia only have the option of continual outpatient or community care in Fairbanks. If this level of treatment is not adequate, they have to seek services in Anchorage (Editorial, 2013). The sole Fairbanks facility providing residential mental health care would discontinue this assistance and significantly curtail other ancillary mental health services. A reorganization in the founding agency (Fairbanks Community Behavioral Health Center) resulted

in the closing of the only residential mental health facility in Fairbanks. Additionally, this restructuring would limit services to those that were financially self-sustaining. The majority of these individuals with schizophrenia do not have access to the financial or agency support necessary for successful treatment with the rebranded Fairbanks organization nor to move to Anchorage.

The magnitude of these concerns for outpatient treatment for clients with schizophrenia in Fairbanks is the catalyst that drives the research question for this research project. The research question is: what steps can counselors, individuals, family and community members take to address the needs of people with schizophrenia, being served on an outpatient basis in Fairbanks, Alaska, in a reliable and ethical fashion?

Literature Review

Memory, work, socialization, social supports, medication compliance, appropriately tailored treatment, and severity of symptoms all play major roles in the quality of life and ability to cope for people with schizophrenia (Brissos, 2011; Eack & Newhill, 2007; Hill, Mayes, & McConnell, 2010; Kail & Cavanaugh, 2013; Ulric & Lentin, 2010). In order to best serve people with schizophrenia, the symptoms used to diagnose schizophrenia, the development and course of the disorder, cultural and gender issues in diagnosis, and suicide and other comorbid disorders must be understood.

Diagnosis of Schizophrenia

The *DSM-5* (American Psychiatric Association [APA], 2013) lists five domains common for all schizophrenia spectrum and other psychotic disorders: delusions, disorganized thought and speech, grossly disorganized or abnormal motor behavior (including catatonia), hallucinations, and negative symptoms. Delusions involve several categories including:

erotomanic, grandiose, nihilistic, persecutory, referential, and somatic. The *DSM-5* (APA, 2013) describes erotomanic delusions as the belief that another person is in love with her or him. Grandiose delusions include the belief that the individual has exceptional abilities, fame, or wealth. Nihilistic delusions include the belief that major catastrophes will occur. Persecutory delusions include paranoid ideology about individuals and organizations. Referential delusions include the false belief that external actions and cues are specifically directed at the individual. Somatic delusions involve concern about physical health and well-being. Delusions are considered bizarre if they have no relevance to cultural norms, including thought withdrawal, thought insertion, and delusion of control (APA, 2013).

The *DSM-5* (APA, 2013) defines disorganized thought or speech as including derailment or tangentiality in answering questions, and in rare cases, giving completely incoherent responses. Grossly disorganized or abnormal motor behavior involves whimsical actions, unpredictable agitation or other actions that detract from goals (including daily living activities). Hallucinations are described as visual or auditory experiences that are clear and vivid, but without external stimulus. This does not mean there is no related event, but instead that individuals may have additional experiences that are not perceived by others. The *DSM-5* explains that negative symptoms include diminished emotional expression, motivation, speech, pleasure, and interest in social interactions.

In the *DSM-5* (APA, 2013), the diagnostic criteria of schizophrenia includes the requirement that symptoms must be experienced for at least six months with at least one month of significant experience in at least two of the following areas: delusions, disorganized speech, grossly disorganized or abnormal behavior, hallucinations, or negative symptoms. Significant impact on level of functioning must also be found in work, social interactions, or self-care.

Differentiation of diagnosis must be made in comparison to autism spectrum, other mood and psychotic disorders as well as substance abuse and other medical conditions. Once the individual has experienced symptoms for more than one year, other specifiers of the disorder should also be included in the diagnosis: number of episodes; acute, remission (partial or full), or continuous; presence of catatonia; and may include current severity scale. Depending on which symptoms are present for an individual with schizophrenia, he or she will experience the disorder differently from others with the same diagnosis (APA, 2013). Of the five domain categories associated, only some of the defined characteristics of a given domain are needed if significantly observed. An individual's culture religion, differences in body language, language barriers, emotional expression and eye contact are important factors to consider when making a diagnosis (APA, 2013).

While the last three diagnostic criteria in the *DSM-5* (APA, 2013) are only related to differential diagnosis from other disorders, the first three are very important in understanding how a person with schizophrenia appears to friends, family, and community, especially when we consider that symptoms usually build over time from onset. Others may see these symptoms as the person becoming eccentric, lazy, or apathetic, as six months with varying severity of behavior changes must be observed before a person can be diagnosed with schizophrenia. Family and other authority figures may have attempted and failed to make the person change behaviors and support for the person will likely have started to fall apart as a result.

Development and Course

Men most commonly experience the onset of schizophrenia in their early 20's and women most commonly experience the onset in their late 20's (APA, 2013). Women between 40 and 55 years of age are also more likely than men to have onset of symptoms; this also may

be considered for differential diagnosis (APA, 2013). Age and gender also show significant differences in what domains are experienced, the severity of presented symptoms and the likelihood of successful remission or recovery. Proper diagnosis is difficult in children and early onset of the disorder is more likely to lead to worse outcomes and severe negative symptoms.

Individuals with active symptoms of schizophrenia may lack insight or have an impaired awareness of their illness, known as anosognosia (APA, 2013). The *DSM-5* (APA, 2013) explains that the lack of awareness is a symptom of schizophrenia instead of a coping strategy or a byproduct of cognitive dissonance. Mote, Stewart, and Kring (2014) found that people with schizophrenia often experience emotions even when negative symptoms suppress emotion expressivity. Gard and colleagues (2014) found that not only were emotional experiences not suppressed, but that people with schizophrenia set more pleasure-seeking goals and have higher anticipation of goals leading to pleasure than people without schizophrenia. Brissos and colleagues (2011) found that quality of life evaluation (as measured by the client) did not significantly correlate with social functioning (measured by the therapist), despite the previous perception that psychosocial functioning and subjective quality of life are important when measuring the success of treatment of people with schizophrenia. Subjective quality of life had been determined to be an acceptable measure of the impact of negative symptoms and co-morbid depression. Brissos and colleagues showed that clinicians are unable to confirm how well patients are doing from self-reports and there was a difference in perceived quality of life compared to the measured social functioning in patients with more severe or unstable symptoms. Despite the difficulties in measuring and evaluating quality of life, Eack et al. (2007) found that unmet needs and social support are still important contributors to the quality of life of people with schizophrenia.

Prognosis and Treatment

Dixon et al. (2010) described eight treatment recommendations for people with schizophrenia based upon their evidence-based research: assertive community treatment, cognitive behavioral therapy, family-based services, psychosocial treatment for substance abuse, skills training, supported employment, psychosocial interventions for weight management, and token economy. Families, friends, peers, and employers are all considered natural supports for people with schizophrenia. Given that outpatient treatment has become more common than inpatient treatment or treatment in residential settings and the need to rely on natural supports is now even greater, Dixon and colleagues recommend that families friends, peers, employers and relevant local agencies are involved with all eight forms of treatment.

Maxmen, Ward, and Kilgus (2009) point out that current treatment for people with schizophrenia includes an emphasis on improving quality of life instead of curing the disorder. This approach is considered best practice in the *DSM-5* (APA, 2013), which shows that most people with schizophrenia will never be fully cured of the disorder. Maxmen and colleagues explain that improving quality of life includes minimizing symptoms, preventing suicide, averting relapses, improving social and occupational functioning, enhancing self-esteem, and helping and enhancing the support structures of the person with schizophrenia. There are three main stages of treatment that determine the forms of care required by a client with schizophrenia: acute, transition, and chronic. Acute care includes treatment to help stabilize the client's thoughts feelings, and behaviors; reducing noticeable psychotic symptoms, and managing the safety of the client and others around them. Transition care includes maintenance of acute care actions between health care providers or locations, such as integrating treatment plans between residential and outpatient treatment. Chronic care involves continuous treatment of the client,

usually through outpatient services and pharmacological treatment. Medications are often used to treat positive and/or negative symptoms through a combination of antipsychotics, antianxiety, and antidepressants; sometimes sedatives are also included. Medications are used throughout treatment, with a variety of types and dosages possible during each stage of treatment.

Acute Care: Hospitalization

Maxmen and colleagues (2009) state that the first step in hospitalization of a client is to prevent the client from harming self or others. This may include the use medication, seclusion, or physical restraints. There is some ethical debate as to the extent of use of restraints, including personal testimony by Saks (2007) who explains the pain and terror felt by clients under restraint. Medication including sedatives may make the client less responsive while still fully experiencing the hallucinations, leading to more aggressive behaviors. Maxmen and colleagues explain that during hospitalization, medication is rapidly administered to a client to help quickly address positive and negative symptoms, then the initial diagnosis and brief therapy is initiated, and a regular medication regimen is established. Maxmen and colleagues explain that the majority of the time spent in the hospital is used to initiate therapy while medication has a chance to produce significant effects, which may take weeks.

Ascher-Svanum et al. (2010) studied predictors of repetitive relapse for people with schizophrenia and found that younger adults with schizophrenia are more likely to relapse (about 91% of total participants after one year in outpatient care). Those who relapsed repetitively also had: a) more severe positive and negative symptoms; b) a continuing history of relapse; c) lower rates of medication adherence; d) higher risk of substance abuse disorders; and e) more depressive symptoms, arrests, and victimization by others. In addition to re-hospitalization, young adults with schizophrenia who relapse also had a higher use of emergency services.

Overall, the population who relapsed had less social supports and relied heavily on health insurance (mostly Medicaid) to pay for services. Ascher-Svanum and colleagues found that the individuals who continue to relapse have annual mental health costs that are roughly five times the amount paid by clients who do not experience regular relapse.

Transition Care: Staying in Touch

Maxmen and colleagues (2009) explain that there are several aspects of clients' well-being that must be assessed routinely during the transition of care from inpatient to outpatient and from one therapist to another. These include: suicidal behaviors, medication non-adherence, therapy non-adherence and non-compliance, inadequate (financial, social, and family) support, and inadequate recreation. The problems are especially important to address for during transition care, but need to be monitored during chronic care as well.

Silverstein and colleagues (2006) reviewed research from the 1980s and 1990s regarding the behavioral rehabilitation of people with schizophrenia. The review suggested that 10% of people with disabilities in the United States have schizophrenia and very few of these people are able to maintain constant employment, with only 10-30% of people with schizophrenia in the United States employed at any point in time. Silverstein and colleagues developed an intensive, inpatient behavioral rehabilitation program for patients with schizophrenia and found that maximum benefit of treatment occurred when patients consistently followed a regular medication regimen and utilized behavioral therapy techniques (including positive reinforcement and extinction). The behavioral methods used in developing the program included reinforcing only appropriate and exemplar behavior. These interventions involve shaping (reinforcing behaviors that are close approximations of appropriate behavior), giving specific feedback to patients including reason for reward, and not reinforcing failures by giving attention to the

patient at time of failure. There was a strong emphasis on extinction of inappropriate behaviors by not responding to the patient engaging in such behaviors. In the rare situation in which extinction is not useful, the caregiver was to analyze the situation (including feelings and intentions of the patient, limits, and possible alternative behaviors). The researchers found that behavioral treatment manifests improvement, while cognitive rehabilitation has minimal effect on people with schizophrenia who are transitioning from inpatient to outpatient services. The program utilized in this study shows better results than many other pharmaceutical company sponsored studies, but it still had a 49% 2-year re-hospitalization rate for individuals who left inpatient treatment into outpatient community care. Maxmen and colleagues (2009) also found that people with schizophrenia, who have been chronically hospitalized, tend to function better in communities after having been gradually transitioned from inpatient living. Staying in day treatment programs or halfway houses allows the client to slowly adapt to community life while rebuilding support networks, seeking employment, and finding new forms of recreation.

Herbener, Rosen, Khine, and Sweeney (2007) find that people with schizophrenia also may experience anhedonia. People with schizophrenia, Herbener and colleagues explain, are more likely to remember negative imagery and concepts than positive. The anhedonia experienced by people with schizophrenia is both physical and social, with symptoms occurring after emotions would normally be processed into memory. In similar fashion, Thornton et al. (2007) found that people with schizophrenia do not experience improvements in working memory from rewards, though they receive similar benefit in long-term memory compared to people without schizophrenia. Contrary to the findings of Thornton and colleagues, Ahn et al. (2011) ascertained people with schizophrenia are more likely to want immediate, smaller rewards rather than larger, delayed rewards. This finding shows that while they may receive

similar long-term benefits, people with schizophrenia tend to perceive immediate rewards to be more important compared to people who do not experience schizophrenia. The difference in perception was found to be true across all samples of people with schizophrenia, despite any concurrent substance use, employment, medication, or other variables. Ahn and colleagues explain that the desire for immediate reward may also be due to greater impulsivity.

Dixon and colleagues (2010) found that coping skills were needed to improve daily living interactions and activities. Activities and interactions include independent living skills, social interactions, and community function skills. As skills training uses behavioral modalities, family and community support significantly improves success of behavioral modification needed for skills training and other coping strategies by supporting behavioral modification. The use of a token economy was suggested as part of long-term inpatient or residential care. The purpose of token economy strategies is to support behavioral interventions. Similar to skills training, these strategies are most successful when all interactions remain consistent with treatment. As people with schizophrenia are more likely to manage symptoms if they rely heavily on family support, teaching families to use the token economy is necessary with outpatient clients as well as in residential care.

Dixon and colleagues (2010) found that the use of cognitive behavioral therapy (CBT) to develop cognitive and behavioral coping strategies, in conjunction with medication, tends to help reduce the severity of symptoms perceived by clients and counselors. Family and group therapy were found to be as useful as individual therapy in reducing symptoms and developing coping skills of individuals with schizophrenia. Evidence of success with CBT is not conclusive, so other forms of therapy should not be ruled out. In regard to the findings of Silverstein et al. (2006), it should be noted that the reason cognitive rehabilitation yielded limited efficacy may

have been due to limitations on the cognitive techniques used and not on cognitive rehabilitation as a whole.

Chronic Care: Remission and Relapse

Several factors may play an important part in transitioning and maintaining treatment and remission of schizophrenic symptoms for clients. Gender may play a major role in adapting to community life, according to Vila-Rodriguez (2011). Women with schizophrenia have better social functioning during chronic care than men given similar severity of disorder. Dixon and colleagues (2010) found that assertive community treatment (ACT) helps reduce noncompliance, reclusion, and re-hospitalization for people with schizophrenia. ACT includes regular and direct client contact, medication management, case management, outreach, and contact among support groups. ACT helps clients become less reliant on emergency services, but increases use of outpatient services. ACT increases clients' use of outpatient services while reducing clients' reliance on emergency services. ACT has also been found to decrease symptomology, support medication compliance, increase willingness of clients to utilize natural supports, and increase client and family satisfaction with therapy.

Demonstrating how compliance and adherence to treatment occur remains a concern. Beebe (2010) explains that people with schizophrenia commonly reported auditory hallucinations, forgetting appointments, and noncompliance with medication. Beebe used a tele-nursing intervention for gathering reports of problems for participants in community-based treatment. Beebe found that forgetting medication, loneliness, anxiety, and arguments at home were all reported by outpatients with schizophrenia who were stable in treatment and taking medication.

Silverstein and colleagues (2006) noted a significant relapse problem with clients in outpatient care who lack of support after leaving hospitalization. Given that people with schizophrenia are expected to rely on a social network (including friends and family), Gutierrez-Maldonado, Caqueo-Urizar and Ferrer-Garcıa (2009) studied the outcome of psycho-educational intervention on the attitudes of relatives of patients with schizophrenia. Gutierrez-Maldonado and colleagues found that family members possessed a more positive attitude toward the person with schizophrenia with the psycho-education intervention.

Other problems and disorders can arise during outpatient care for people with schizophrenia. Pallanti, Quercioli, and Hollander (2004) found that 36% of schizophrenia patients have a co-morbid social anxiety disorder or other, rarer cases of anxiety disorders. The prevalence of co-morbid social anxiety disorder was lowered to about 17% for people with schizophrenia who received impatient acute care services. Pallanti and colleagues also confirm that medication, combined with cognitive behavioral treatment, resulted in clinically significant improvements in quality of life, social anxiety, and social phobia symptoms in the majority of treated patients.

Socialization and Work

According to Kail and Cavanaugh (2013), significant factors for personal development and quality of life are: socialization, work, memory, and intelligence. Unfortunately, people with schizophrenia may experience profound impairment in these areas and the severity of symptoms increase the level of dysfunction for these individuals. These factors may lead to problems in interactions with others (including family members), reactions to visual and verbal stimuli, medication non-adherence, counseling non-adherence, and even, in rare cases according to Dailey, Chinman, Davidson, and Garner (2000), aggressive behaviors.

Dailey and colleagues (2000) found that, even though only a small percentage (6%) of people with severe mental disorders were perceived as threatening, the general population, including members of communities where people with schizophrenia are being integrated, tend to perceive most individuals with severe mental disorders as being violent and dangerous. This perception can lead to less community support for outpatients with schizophrenia and lower willingness to utilize positive reinforcement strategies. A more recent study in Spain by Bobes, Fillat, and Arango (2009) reported similar findings of aggressive behaviors, with only 5% of participants with schizophrenia, who are appropriately medicated, having had recent aggressive behaviors. Overall, slightly more than 2% were verbally violent and only 1% of participants actually became physically violent.

Cellard, Lefèbvre, Maziade, Roy, and Tremblay (2010) found that most people with schizophrenia have limited ability to pay attention to multiple stimuli at once and reach attention saturation, which may lead them to become overwhelmed far sooner than others. Ulric and Lentin (2010) similarly found that people with schizophrenia feel the need to limit how much they accomplish and limit social contact in order to help cope with stimulation and stress found in everyday life. Unfortunately, Ulric and Lentin found that few businesses (especially in Australia where their study took place) actually want to support the employment of people with severe mental illness, despite the government policies that advocate such. Employers are intimidated by stereotypes, including aggression of schizophrenia, and refrain from employing these individuals. Despite the stereotype of aggression, Brissos and colleagues (2011) found that clients with schizophrenia in remission had more problems with work and relationships than aggressive behaviors.

Dixon and colleagues (2010) recommended that treatment for people with schizophrenia should include supported employment. Supported employment in this regard means help finding and placing individuals in jobs quickly. Employment improves mental health and vocational services and job coaching can assist the individual in developing necessary work skills. Kurtz, Donato, and Rose (2011) found that crystallized intelligence (described below) plays an important role and verbal cognitive functioning also reveals the interplay between role experience of having a job and living in a community. The more experience in a particular job field, the less impaired a particular individual with schizophrenia will be in that field. Moving into a new job field will more likely result in impairment. The individual with schizophrenia is more likely to be able to continue working in jobs similar to previous experience.

Memory and Intelligence

Based on literature regarding the memory of clients with schizophrenia, it appears there are several limitations to both perceived and actual intelligence of people with schizophrenia: (a) false memory (Mayer & Park, 2012), (b) becoming overwhelmed by content saturation (Cellard et al.; 2010), (c) anhedonia and reward-based learning (Ahn et al., 2011; Herbener et al., 2007; Thornton et al., 2007), and (d) other cognitive limitations on rehearsal-based and language learning (Cellard et al., 2010). While people with schizophrenia do not lack pattern recognition and implicit memory, they usually respond more slowly to patterns and to learning those patterns (Ahn et al., 2011; Grillon, Gourevitch, Giersch, & Huron, 2010; Mayer & Park, 2012).

Kurtz and colleagues (2011), found that the level of crystallized verbal skills strongly correlated with the following cognitive functioning measures: working memory, problem-solving, visual vigilance, verbal learning, and processing speed. Patients with high crystallized verbal skills had little to no impairment in any of these, patients with moderate crystallized

verbal skills were impaired in three of five (verbal learning, visual vigilance, and processing speed), and those patients with extremely limited crystallized verbal skills were impaired in all five measures. Results were similar despite the complexity of the schizophrenia experienced by patients.

Based on the Kurtz et al. (2011) findings, it can be assumed that personal experience (or crystalized intelligence) plays a more important role than fluid intelligence (which is the aptitude to learn and adapt). The more experience in a particular job field, the less impaired a particular individual with schizophrenia will be. However, moving into a new job field will more likely result in impairment. Similarly, the limited cognitive ability and learning patterns explained by Cellard and colleagues (2010) may limit the quality experience in a job for a person with schizophrenia. Cellard and colleagues also found that egocentric, mnemonic learning might be a more useful tool for people with schizophrenia. This finding also leads to the possibility that people with schizophrenia might have limitations in fluid intelligence as well, given the likelihood for false memories indicated by Mayer and Park (2012).

Cellard and colleagues (2010) explain that short-term memory is also found to be severely impaired in people with schizophrenia, limiting cognitive functions, behaviors, rehearsal-based learning, and language learning. People with schizophrenia often experience forgetfulness, disorganized thought, and poor problem solving ability. Similarly, Cellard and colleagues found that people with schizophrenia have more limited short-term memory due to selective attention.

Mayer and Park (2012) define working memory as short-term storage of information used to actively guide behavior and explain that people with schizophrenia are found to be impaired in working memory, especially in spatial recognition. Specifically, Mayer and Park (2012) found

that working deficits in people with schizophrenia are due to an increase of false memory responses. These false memories were most likely due to difficulty in processing new information and the belief that their memory was failing. Grillon et al. (2010) also found spatial memory limitations in people with schizophrenia, specifically in the inability to recall the last word displayed at a specific location, but not in just repetition of words.

Suicide Risk and Comorbid Disorders

Substance abuse and weight gain were found by Dixon and colleagues (2010) to be commonly linked to lack of coping skills and inhibitions for people with schizophrenia. Treatment recommendations for both were similar. Motivational and behavioral treatment, coping skills training, and relapse prevention are all common forms of treatment for both substance abuse and weight loss interventions. Weight gain was found to be common among people taking first and second generation antipsychotic medications, also known as typical or neurolepitics (first generation) and atypical antipsychotics (second generation). Examples of typical antipsychoyic medications are chlorpromazine and haloperidol. Examples of atypical antipsychotic medications are aripiprazole and paliperidone. El-Mallakh (2013) found that diabetes mellitus is common among individuals with schizophrenia. This may relate to the weight gain from antipsychotic medications, but also may relate to amore sedentary lifestyle, lack of knowledge of nutrition, smoking and lack of coping strategies for interpersonal stress from caregivers and family.

Pallanti, Querciolli, and Hollander (2004) found that social anxiety is a common symptom for people with schizophrenia, and they correlated with the severity of other symptoms of schizophrenia. In their study, Pallanti and colleagues found the prevalence of patients with schizophrenia and co-morbid social anxiety disorder was reduced to roughly 17% in hospital

care of acute adult services, rather than the 36% found in the sample of this study of outpatients. Therefore, findings indicate that outpatients with schizophrenia are at much greater risk for social anxiety symptoms. Results from this study also suggest that tying medication in with cognitive behavioral treatment manifested clinically significant improvements in quality of life, social anxiety, and social phobia symptoms in the majority of treated patients.

Friends, Family, and Community

Brissos and colleagues (2011) found that participants had more problems with work and relationships than aggressive behaviors for clients with schizophrenia in remission and that quality of life evaluation (measured by the client) did not significantly correlate with social functioning (measured by the therapist). Clinicians are often unable to confirm how well patients are doing from self-report assessments. There is also a difference in perceived quality of life from assessed measures of social functioning, especially in patients with more severe or unstable symptoms. These findings directly relate to the lack of treatment adherence and outcomes for people with schizophrenia receiving outpatient care.

Dixon and colleagues (2010) found that family interventions significantly reduce relapse and re-hospitalization for people with schizophrenia. Treatment adherence, perceived stress, and work outcomes were also found to improve. Family members also benefitted; they reported lower distress and better relationships among family. Family interventions include coping skills related to symptoms, crisis interventions, emotional support, and psychoeducation. In addition to lessening symptoms, Smerud and Rosenfarb (2011) found that family psychoeducation lessened the escalation of symptoms and signs during the prodromal phase (the point that signs of symptoms occur before the first acute psychotic episode) and lower chances of family rejection. Smerud and Rosenfarb suggest that family psychoeducation and involvement should be included

early in treatment to prevent worsening of symptoms. Severity of symptoms was found to directly relate with willingness of family to support the family member with schizophrenia (Smerud and Rosenfarb; 2011).

Weisman de Mamani, Weintraub, Gurak, and Maura (2014) found that a CBT approach that is a culturally informed treatment strategy significantly reduced schizophrenia symptoms. Weisman de Mamani and colleagues' culturally informed treatment included family collectivism, psychoeducation of symptoms, spiritual coping, communication, and problem solving. They found that when including all these domains, rate of success between ethnicities were similar. Dixon and colleagues (2010) warned that while CBT techniques have had some success with treating some obvious symptoms of schizophrenia, research and developed courses of treatment have not been conclusively reliable for each individual or symptom.

Among Asian-Americans Lee, Yamada, Kim and Dinh (2014) found that having supportive families was still required, but continuous and direct involvement of family members in treatment was not necessary for the successful treatment. Upon further investigation, the Asian-Americans with schizophrenia were more concerned about burdening families than successful management of symptoms. Thus, while family support may be helpful, sociocultural norms may impede family interactions.

Application

The purpose of this research project is to provide counselors, individuals with schizophrenia, their family members, and other interested parties with a better understanding of the needs of people with schizophrenia. This project identified the needs of individuals with schizophrenia in outpatient care, offers factual information on integrating these individuals into

family and community life, and provides information on potential support networks. This project is tailored to the Fairbanks area.

The application for this project is a website (https://sites.google.com/a/alaska.edu/helping-people-with-schizophrenia-in-fairbanks/) that provides general information about schizophrenia, with sections based on the type of interested user (person with schizophrenia, family member, friend, community member, or counselor), as well as contact information for available resources. Each section is tailored for the appropriate user. Emphasis is on promoting positive relationships with people who experience schizophrenia and promoting the use of best practice models. The information provided is also be tailored to life in the Fairbanks, Alaska community.

Conclusion

Memory, work, socialization, social supports, medication compliance, appropriately tailored treatment, and severity of symptoms all play major roles in the quality of life and ability to cope for people with schizophrenia (Kail & Cavanaugh, 2013). Memory and cognitive functioning and how schizophrenia influences these are still being explored (Ahn et al., 2011; Cellard et al., 2010; Grillon et al., 2010; Herbener et al., 2007; Mayer & Park, 2012; Thornton et al., 2007). Work and socialization are highly important for people with schizophrenia, despite difficulty to measure progress. (Brissos et al., 2011;Dixon et al., 2010; Eack et al., 2007; Hill, Mayes, & McConnell, 2010; Ulric & Lentin, 2010). All of these factors appear to require the support of others, whether the support is from a family member, friend, community member, or counselor. The best solution is for everyone to be involved, or at least more educated about expectations and interactions with people who experience schizophrenia. In Fairbanks, Alaska where weather hinders socializing and available services are limited, building many strong

support resources is incredibly important to give people with schizophrenia the best chance of recovery and a stable quality of life.

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Appendix

Website Address: https://sites.google.com/a/alaska.edu/helping-people-with-schizophrenia-in-fairbanks/

Introduction

Diagnosis

Schizophrenia is a difficult mental health disorder that many people deal with. Approximately .3%-.07% of the world's population has been diagnosed. In other words, roughly 1 in every 200 people in an average community experiences this disorder. If all people who have been diagnosed with any schizophrenia spectrum disorder are included, about 3% of the world has a psychosis-related disorder, or 3 in every 100 people. Each person's experiences schizophrenia is unique. However, the major traits of schizophrenia are:

- Delusions
- Hallucinations
- Disorganized thoughts, behavior and speech
- Diminished expression, thought, emotions, and action
- Symptoms must be present for more than 6 months
- Significant change in work, interpersonal relations, or self-care

Each of these areas can be experienced in very different ways. Delusions can be oriented toward grandiosity, persecution, referential cues, physical effects, or religious. People with schizophrenia can experience their thoughts being controlled by outside forces, ideas being placed directly into their minds, or having ideas removed from them. Hallucinations include a variety of sensory-based experiences, with audible hallucinations being the most common. An individual experiencing hallucinations may experience them while awake or asleep.

The Fairbanks Community

Currently, there are no residential facilities in Fairbanks, Alaska for people with severe mental health concerns. The Fairbanks Community Behavioral Health Center declared bankruptcy and reopened as Fairbanks Community Mental Health Services. Few options are currently available for both mental health counseling or for housing. There are several agencies that can help people with mental illnesses or other disabilities locate necessary resources, but navigating which agency is best suited to help each person with schizophrenia is challenging, especially for the people who experience schizophrenia.

Finding appropriate care in Fairbanks can be difficult. Depending on the current needs of a person with schizophrenia, different agencies will be more appropriate to contact than others. If the person with schizophrenia is currently experiencing a psychotic episode, Fairbanks Memorial Hospital is the best to contact. If the person needs regular counseling services, FMH can refer him or her to Fairbanks Community Mental Health, even if they are currently not taking clients. Other counseling agencies may have qualified counselors to work with co-occurring disorders like substance abuse or depression. If the person with schizophrenia has symptoms in remission and is ready to work towards employment and community integration, the Division of Vocational Rehabilitation and Access Alaska may be able to help. Other agencies that may needed to be contacted can help with food, shelter, clothing, and other daily needs.

Purpose

Many people are involved when a person experiences schizophrenia. Aside from the individual are family and friends, classmates, coworkers, educators, employers, landlords, and any other community members who interact with the individual. As mental health and other services will be sought by people with schizophrenia, many more people will be needed to

effectively help each person with schizophrenia to live happy, healthy lives. Each page on the website is directed at a different group member. A contact list for various resources in Fairbanks is also included to help assist in meeting the needs of people with schizophrenia.

People with Schizophrenia

Experiencing Schizophrenia

One of the most important characteristics of schizophrenia is that you will perceive things differently than other people. This does not (just) mean you are having hallucinations, but that your entire experience of events may be different than those around you. You may feel you are thinking, behaving, and acting normally, but how you express yourself is going to be noticeably different than before your first episode. You may express more exaggerated body language or none at all. Other people may not be able to understand you as you speak, possibly to the point of being alarmed at your speech patterns. You are the expert as to how you feel, especially if you have this disorder. Other people will not be able to reliably read your body language or other subtle cues. You may have heard voices or just background noise that you discredited. Until you started reacting to changes, others may not have noticed what you struggled with. You might be just as alarmed as other people around you, but the experience will likely be very different, even while taking medications.

Many people with schizophrenia have a hard time staying on medications for various reasons. You may notice that you still occasionally experience things that you know are not real and you might believe the medication is not working. You may hate how the medications make you feel. Your body might just not be reacting correctly with the medication. It is very important to effectively communicate your reasons for not wanting to take medication:

Be patient with other people, they cannot understand your unique experience.

The most common experience of treatment for those with schizophrenia occurs in 3 stages: hospitalization, transition and chronic care. There are many beginnings to experiencing symptoms of schizophrenia. You may have been hospitalized at Fairbanks Memorial Hospital as acute and pronounced effects of the disorder affect your actions, but you may have noticed little things change in your life even before that incident. If not sent to a hospital, you hopefully have instead seen a counselor more than once a week, maybe even daily. You may have been required to be restrained by physical means or medication. This may have been a traumatic event for you. The people who did these things probably intended to help, but caused pain instead. The reason you were sent to a hospital in the first place was that someone in your life believed you were going to harm yourself or others. Unfortunately, this may have happened to you several times if you did not get help developing coping skills at the same time.

The transition period of treatment is the time when people with schizophrenia normally get help developing methods to cope with symptoms. During this time, re-hospitalization is common. You may experience several acute episodes over several years before you feel stable in your life. During this time you will need to develop enough coping skills and wait out more vivid experiences in order to adhere to regular counseling and medication regimens.

Chronic care occurs when a person with schizophrenia is able to reliably seek counseling and medication. This unfortunately does not mean you will be done with acute episodes, but they will hopefully occur less often and less vividly. Medication will be more consistent, whether or not you perceive it as being helpful. There will be many problems that will be noticed by you or others that have changed you since you started experiencing symptoms. The most noticeable areas that are affected and where you might want help are: memory, experience, and how you interact with others.

Memory

People around you might notice you are having trouble remembering things. Maybe you had trouble remembering an appointment or to take your medication. Maybe you remember an event differently than someone else. This does not mean you have simply become forgetful; this is actually due to the fact that you memorize things differently. You may have actually experienced things differently, but you may have a false memory, where for some reason, you remember something else occurring during an event than actually happened. This change in memory can happen to anyone, but people with schizophrenia experience it more often and more rapidly. This difficulty with reliable memory makes learning new skills a challenge, no matter the setting.

Experience

Relying on what you already knew before you started having symptoms will lead to the best results in coping skills, independently living skills, and work. Teenagers who have not ever lived on their own or developed work experience may be overwhelmed trying to learn these and learn how to cope with their illness. Adults who have learned to live on their own and work will be able to spend more time developing coping skills. This does not mean that work and life will be unaffected (after all they must be impacted to receive a diagnosis of schizophrenia), but that, as long as they are able to live and find employment in the same area they did before, they will learn to adapt more easily as symptoms diminish.

Family Members

It will be very useful to family and friends of a person with schizophrenia to read the section *People with Schizophrenia* to get an idea as to how the person experiences symptoms and interactions with others. As with people with schizophrenia, one of the most important things for you to be concerned with is being patient with the family member who experiences

schizophrenia. As the person with schizophrenia cannot see how they are acting, others cannot see what people with schizophrenia are trying to express. They may be over- or under-expressive, they may have interrupted speech and behavior patterns, but they may not experience the difference in behavior and speech the same way.

Family Support

Family support is needed in many ways to best help people with schizophrenia. Support includes: emotional, financial, daily living, and scheduling. Many studies have shown that treatment has far better results when family is actively supportive of the person with schizophrenia. Counselors may even ask family members to help the person with schizophrenia develop needed skills. Benefits found in family support are reduced symptoms, improved treatment adherence, improved life and work skills, and greater satisfaction with treatment. Family counseling has even been shown to dramatically improve the rest of the family's quality of life, as they are better able to navigate the changed relationships. The family may have already experienced significant, negative changes since the onset of symptoms in the person with schizophrenia. Change will likely require a great deal of effort, but the person with schizophrenia has a lot of work to do too to successfully adapt to the mental illness.

Support does not just mean understanding the mental illness and what to expect, but helping to challenge the person with schizophrenia to relearn how to interact socially among family members and friends. Family members can also set goals for the person to attain that may seem out of reach in the moment. The important thing to consider is to not punish failure. Instead, family members might ask what made the goal difficult to complete at the time. The more realistic goals are to real-life settings, the more likely people with schizophrenia are to be successful in those areas in the future.

Counselors and Paraprofessionals

Diagnosis

Remember that with every diagnosis, people who experience the illness, are not *the* diagnosis. That said, people with schizophrenia have many challenges to overcome in learning to live with schizophrenia. Non-adherence to treatment and noncompliance to medication are part of the symptomology. The insight of the experience of schizophrenia in *People with Schizophrenia* may help counselors and paraprofessionals in developing strategies in working with this population.

Treatment

CBT is the most researched method used to treat people with schizophrenia. Research on specific techniques and methods has not been studied exhaustively to determine which are best for working with schizophrenia. There is high variability of success rates based upon techniques used. This means that while CBT might be have the most evidence, it is not necessarily going to work best with each client or counselor.

Other Concerns

Several studies have found that people with schizophrenia may sometimes become agitated and aggressive, but that they are rarely physically violent. Aggression is sometimes increased when the person with schizophrenia feels restrained.

It is crucial that counselors connect people with schizophrenia to resources outside of treatment in order to provide stability and support while they are learning to adapt to the disorder. In addition to housing and social support networks, employment has also been determined to help promote wellness and skill-building in people with schizophrenia. With Fairbanks Community Mental Health Services no longer having a vocational unit, getting the

client connected with other employment agencies like Division of Vocational Rehabilitation is very important.

Simply making sure clients are medication compliant is not ethically sufficient. Clients need supports and advocacy in place, but must also be allowed to make autonomous decisions for themselves that will not immediately deny services.

Community Members

Other community members should look through this site to determine if you are involved with any other group. You may consider working closely with the individual's mental health counselor to determine what accommodations are necessary as well as best methods to address change in order to promote the welfare of the person with schizophrenia as well as the success of corresponding groups, such as the business or school.

Other community members may want to assist in the advocacy for people with schizophrenia. This may include direct help such as legal advocacy, but could also include advocacy within the community or politically, and for mental health agencies like Fairbanks Community Mental Health Services, in order to better fund and staff agencies that support the expansion or creation of residential and vocational options of those people experiencing schizophrenia or other serious mental illness.

Fairbanks Community Resource List

Emergency Services:

- Fire, Police, Ambulance: 911
- Hospital: 452-8181
- Crisis Line: 452-4357
- American Red Cross: 456-5937

Counseling Services

- Fairbanks Community Mental Health Services, 3830 South Cushman 371-1300
- Fairbanks Counseling and Adoption, 912 Barnette St., 456-4729
- Fairbanks Psychiatric and Neurological Clinic, 1919 Lathrop, Suite 220, 452-1739
- Fairbanks Veteran's Center, 540 4th Ave, Suite 100, 456-4238
- Family Centered Services of Alaska, 1825 Marika Rd. 474-0890
- Hope Counseling Center, 926 Aspen St, 451-8208
- IAC (Interior Alaska Center for Non-Violent Living) 726 26th Ave 452-2293
- North Star Center 474-4955 Substance Abuse Pre-treatment for Detox, 456-1053; residential 456-1045, intake 456-1101
- Ralph Perdue Center 3100 S. Cushman, 456-1101
- Tanana Chiefs Health/Mental Health Services, 122 1st Ave, Suite 600, 452-8251 ext. 3140
- Women and Children's Residential Program, 451-8164

Emergency Shelter:

- Fairbanks Rescue Mission, 723 27th Ave. Call for an appointment 452-5343
- IAC (Interior Alaska Center for Non-Violent Living) Previously WICCA 717 9th, 452-2293

- Love Inc. Emergency Services, 452-5683, 9:00am to 12:30pm

Clothing:

- Rescue Mission, 723 27th, 452-5343
- The Salvation Army, 2222 S. Cushman, 456-2085
- Value Village Thrift Store, Airport Road, 474-4828

Food:

- Stone Soup Kitchen, 507 Gaffney Rd. from 7:30 - 10:00, 456-8317
- Fairbanks Food Bank, 725 26th Avenue, 456-4273
- Immaculate Conception Soup Kitchen, 456-4918

Employment and Training Services:

- Adult Learning Program (ALPA)/GED/ABE), 60 Hall Street, 452-6434
- Alaska Job Center Network, 675 Seventh Ave., Station D

  Employment and Training Services – 451-5967

  Job Information Hotline, 451-2875, Unemployment Insurance, 451-2871
- Carol Brice Family Center, 1949 Gillam Way, 451-6993
- Department of Veterans Affairs/Vocational & Rehabilitation Program 540 4th Ave., Suite 100, 456-4238
- Division of Vocational Rehabilitation, 455 3rd Ave. ste 150 451-3150
- FNA Community Services, 605 Hughes Ave., 452-1648
- FNA Center for Employment, 911 Cushman, Ste 206, 456-2310
- Fairbanks Native Association (FNA), 201 First Ave. (Doyon Bldg.), 452-1648
- Literacy Council of Alaska, 517 Gaffney Road, 456-6212
- Love INC, Quality Life and Mentoring, 452-3876
- Tanana Chiefs Conference, 122 First Ave., Suite 600, 452-8251 (serves AK natives)

- Tanana Valley Campus Workforce Development Center, Ste 106, 604 Barnette Street
    - Financial Aid 455-2832 or 455-2826

Health and Disability Services:

- Access Alaska, 526 Gaffney Rd, , 479-7940
- Alaska Center for Children and Adults, 1020 Barnette, 456-4003
- Alaska RX card: prescription assistance: http://www.alaskarxcard.com
- Chief Andrew Isaac Health Center (ANHS), 1717 W. Cowles St. 451-6682
- Fairbanks Memorial Hospital, 1650 Cowles St., 452-8181
- Fairbanks Resource Agency, 805 Airport Way, 451-8091
- Alaskans Information Line/Alaska 211, 1-800-478-2221
- Hospice of the Tanana Valley, P. O. Box 82770, 474-0311, (fax) 456-1371
- Interior Community Health Center/Dental care available, 1606 23rd Ave., 455-4567
- NAMI Alaska 946 Cowles St. Suite 102 456-4704
- Social Security/Income for Disabled, 101 12th Ave., Room 138, 456-5390,1-800-772-1213
- Therapeutic Recreation Program (FNSB Dept Parks & Recreation) 459-1070

Legal Services:

- Alaska Legal Services Corp., 1648 Cushman, Suite 300, 452-5181 or 1-800-478-5401
- Alaska Lawyers Referral Service, Anchorage, 1-800-478-9999
- Disability Law Center of Alaska, 1949 Gillam Way, Suite H, 456-1070
- Human Rights Commission, 1-800-478-4692
- State of Alaska Ombudsman, 1-800-478-3257